

# National Survey of Pre- and Post-Analytical Performance Measures Used in Newborn Screening Programs

Simran Tiwana, MBA\*

Susan Tanksley, PhD\*

Brad Therrell, PhD §

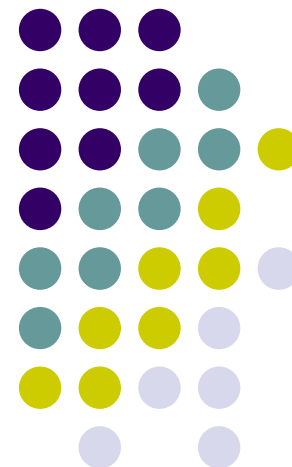
Donna Williams, BS\*

Mirsa Douglass, MBA\*

Colleen Buechner, MS §

\*= Texas Department of State Health Services

§ = National Newborn Screening and Genetic Resource Center





# Introduction

- Performance Measures: Objective way to measure the degree of success of a program in terms of its goals and objectives
  - Number of clients served
  - Change in attitude
  - Change in knowledge etc.
- Performance Measures in Newborn Screening:
  - Unsatisfactory rate
  - Number of serious complications avoided
  - Number of deaths avoided etc.

# The Texas Newborn Screening Performance Measures Project



- Three year grant funded by the Centers for Disease Control (CDC)
- Primary objective to develop evidence-based pre- and post-analytical performance measures to improve the newborn screening system
- Inputs sought via this survey to help in development of performance measures



# Survey Objectives

- To gather information on:
  - Existing pre-analytical performance measures
  - Existing post-analytical performance measures
  - Agencies/organizations to whom performance measures are reported
  - Frequency of reporting to external agencies/organizations
  - Suggestions for future performance measures to improve the NBS system



# Methods

- Web-based survey sent to all 50 States and District of Columbia
- Follow-up via telephone

# Survey Questions



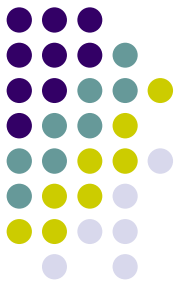
Survey questions allowed structured as well as unstructured (qualitative) responses

- Example: “Within your newborn screening program, which **pre-analytical** performance measures are routinely recorded? *The following list includes some common examples – please be sure to list any additional measures related to pre-analytical phases of newborn screening. (Choose all options that apply)*”
  1. Number of specimens classified as unsatisfactory because of poor specimen quality
  2. Number of specimens classified as unsatisfactory because of insufficient or inaccurate data
  3. Time from collection to receipt in the laboratory
  4. Other (Please Specify)

## A decorative graphic consisting of a grid of colored dots in the bottom right corner. The dots are arranged in a roughly triangular shape, with colors including dark purple, teal, yellow, and light purple. The colors transition from dark purple on the left to light purple on the right, with teal and yellow in the middle.



## Alaska and Hawaii responded as well!

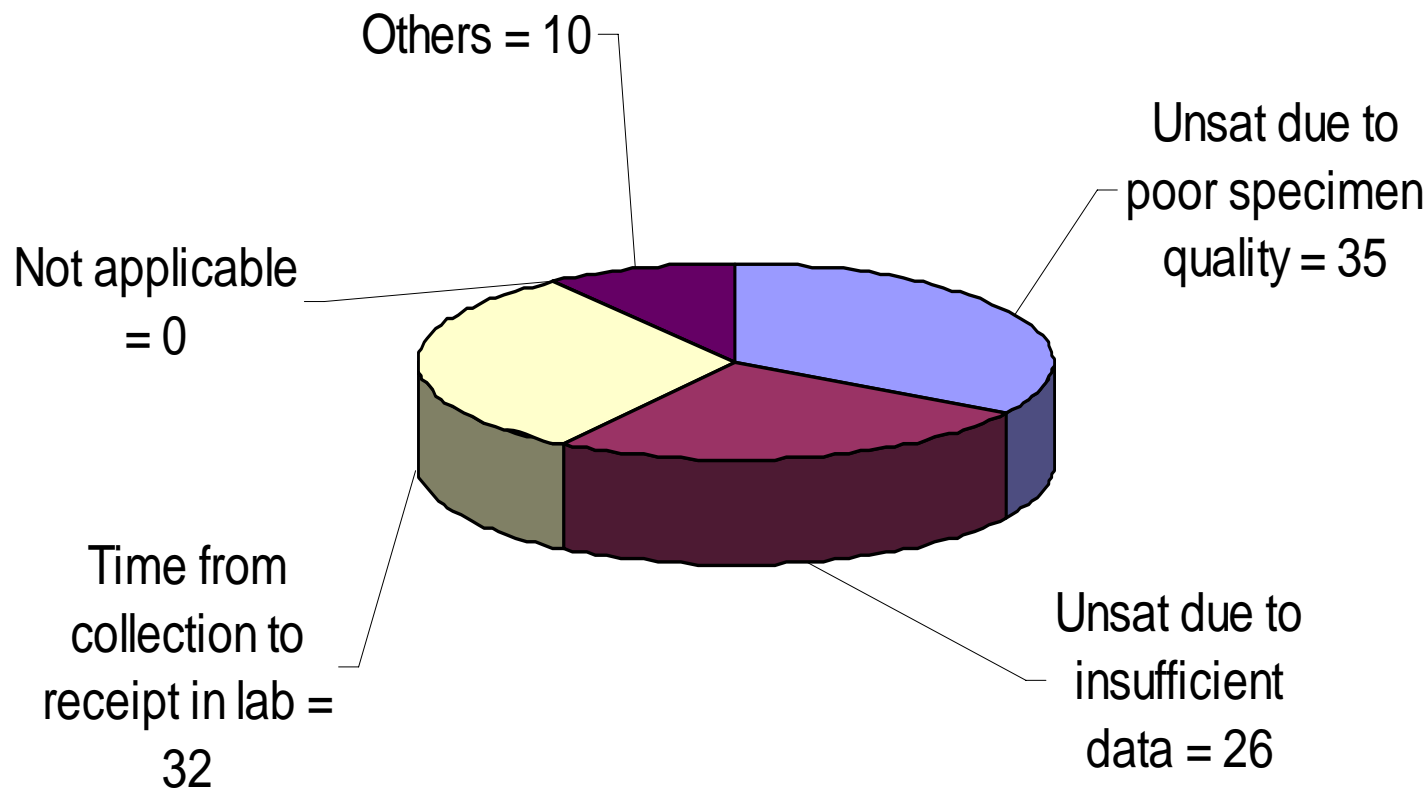


# Results

- Number of surveys sent out = 51
- Number completed = 35
- Response rate = 68.62%
- Average time taken to complete survey = 11 minutes



# Pre-analytical Performance Measures Recorded by State Laboratories (total 103 responses from 35 states)

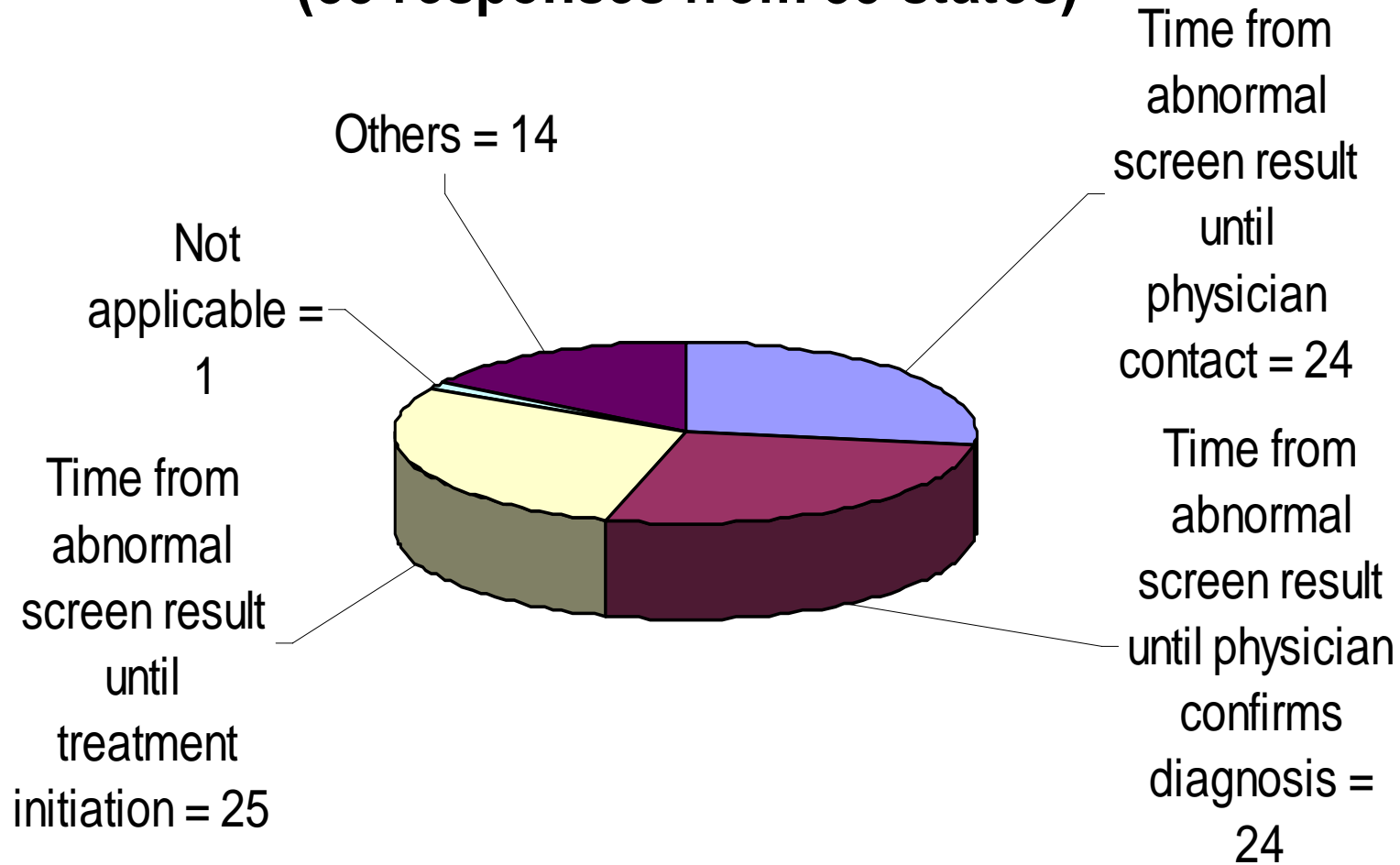


# Other Pre-analytical Measures Collected by States



- Measures related to time
  - Time from birth until specimen collection
  - Time from collection until receipt in the lab
  - Turn-around time within the lab
  - Time from birth until newborn screen result
- Measures related to errors in data
  - Errors in demographic data entry
  - Specimens drawn before 24 hours or after 7 days
- Measures related to missing data
  - Missed screens
  - Refused screens

# Post-analytical Performance Measures Recorded by State Laboratories (88 responses from 35 states)

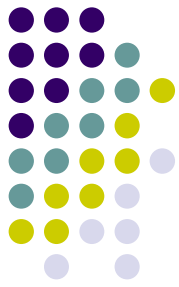
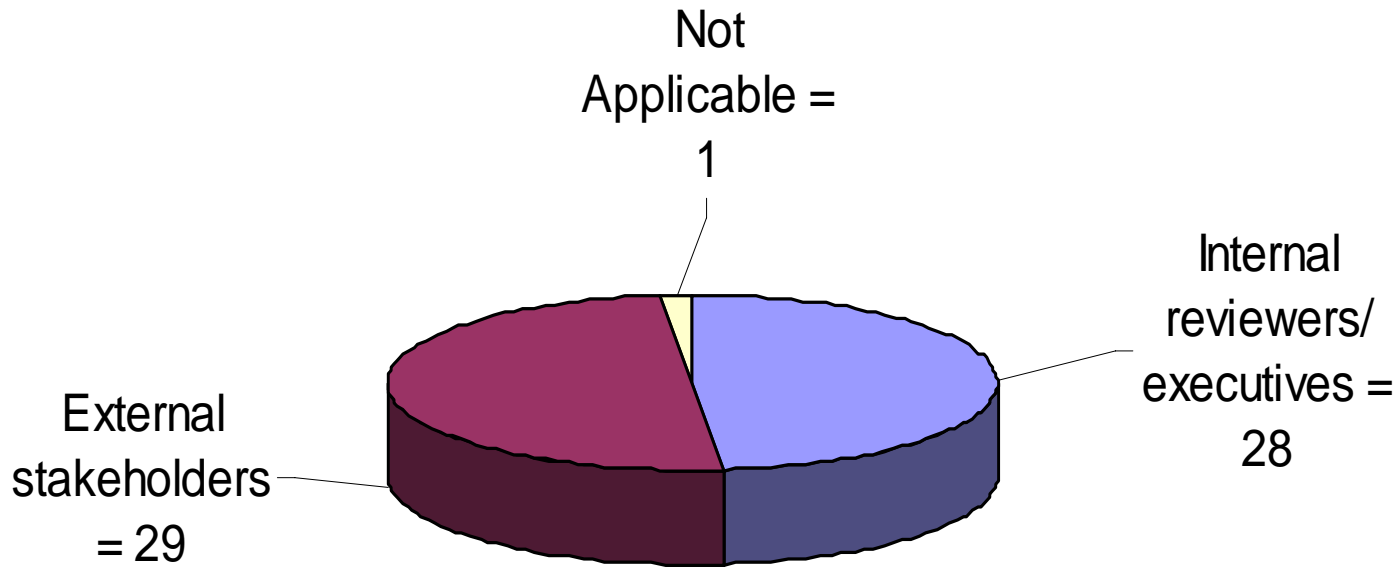


# Other Post-analytical Measures Collected by States



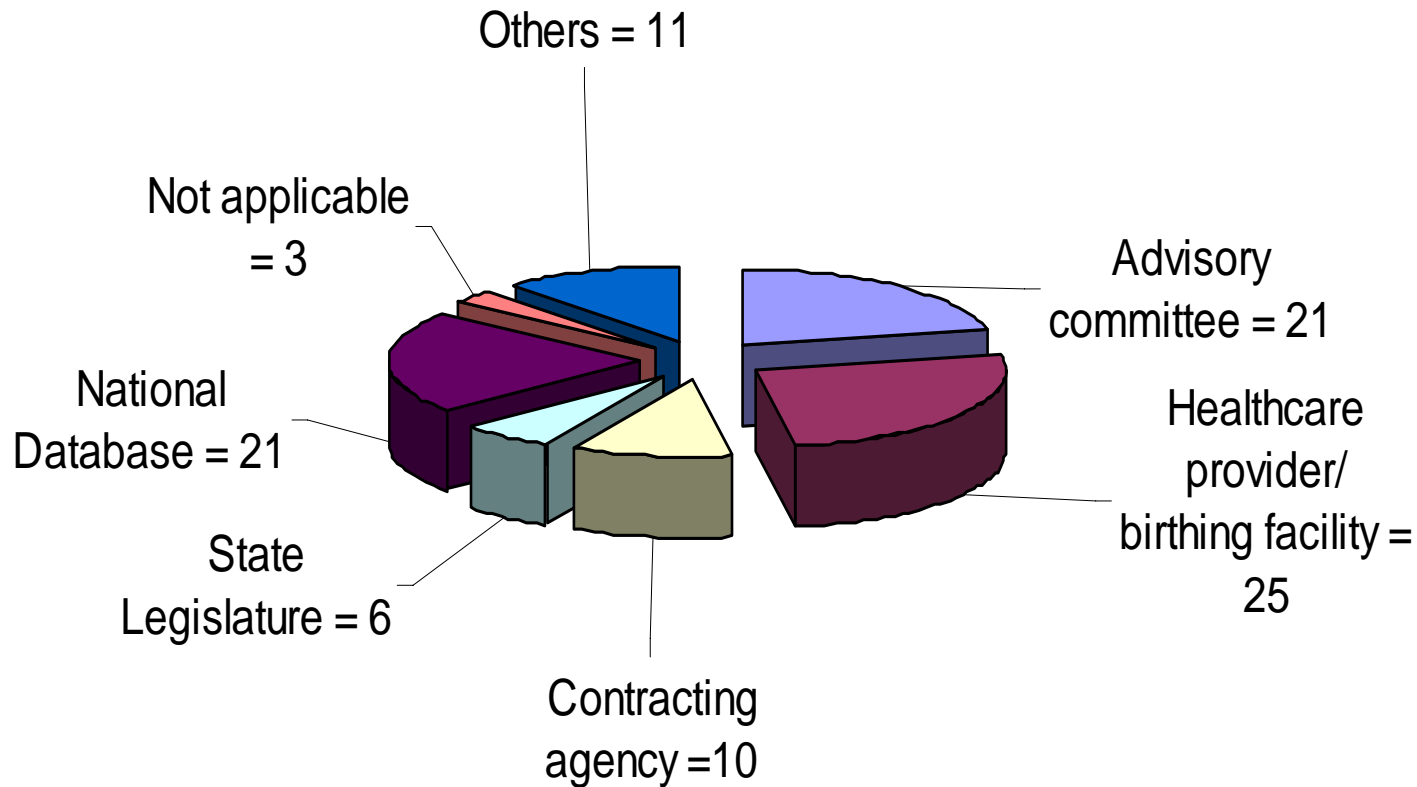
- Time-related
  - Date of physician visit
  - Date of first repeat screen
  - Birth-defects registration date
  - Date of treatment initiation
- Data on abnormal results
  - Percent abnormal results followed
  - Annual list of confirmed cases detected via screening

## Reporting of Performance Measures (58 responses from 35 states)





# Reporting of Performance Measures: Types of External Agencies (97 responses from 35 states)



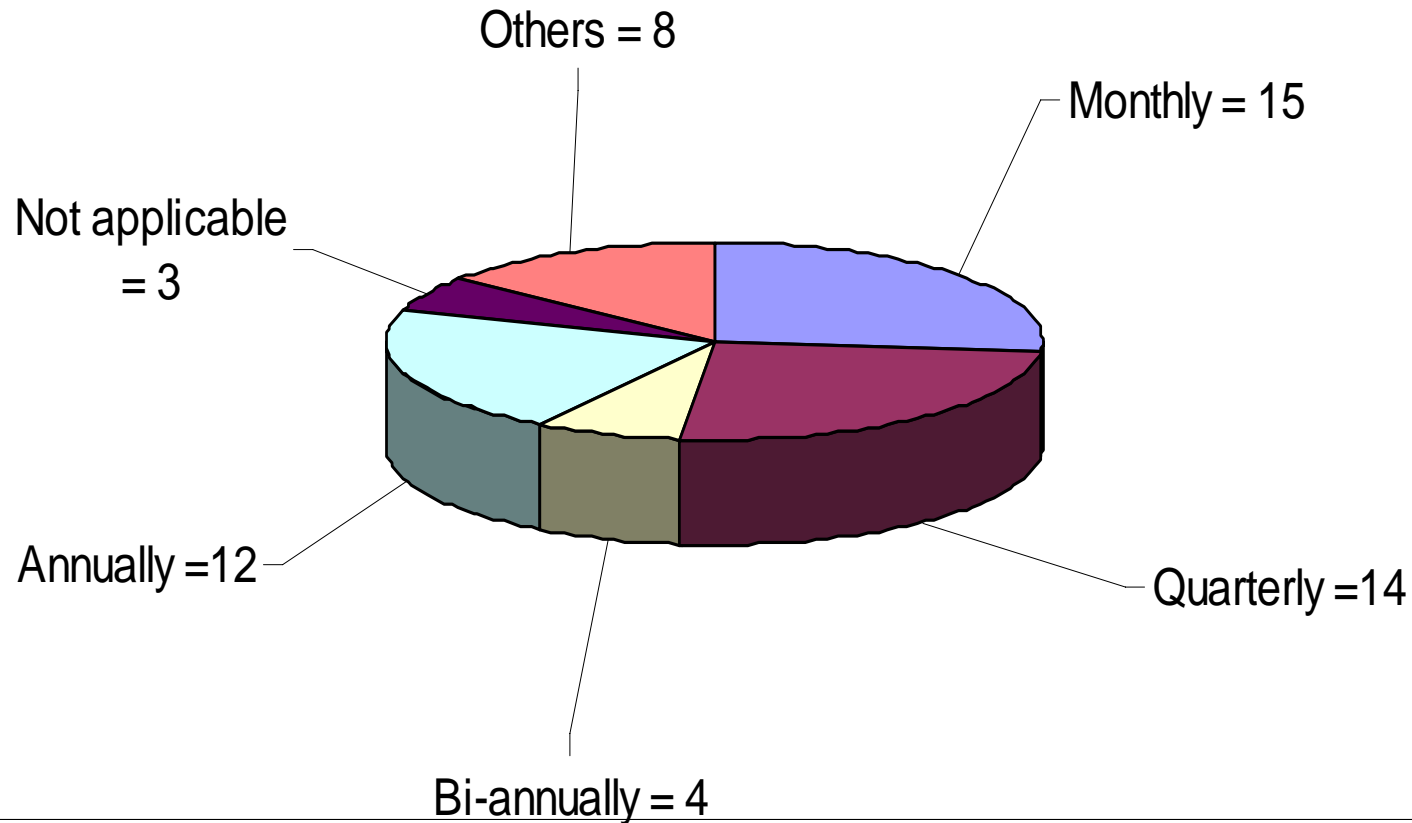
# Other External Stakeholders Notified by State Programs



- Medical sub-specialists
- State Board of Health
- Newborn screening workgroups
- Annual report for distribution and on the newborn screening program website



# Frequency of Reporting to External Agencies (56 responses from 35 states)





# Performance Measures Suggested for Future



- Time-related
  - Time from abnormal screen result to physician notification
  - Time from receipt in lab until final result is obtained
  - Transit time
  - Specimen collection time
  - Time from birth until receipt of screening report by medical home

# Performance Measures Suggested for Future



- Disorder-specific Measures
  - Number (%) of infants diagnosed with Sickle Cell Disease and treated before 2 months of age
  - Number (%) of infants diagnosed with PKU and treated before 7 days of age
  - Number (%) of patients with PKU where Phenylalanine levels were maintained in an acceptable range >80% of the time
  - Specimen collected too soon for testing based on condition (e.g. PKU, MSUD, CH, CAH etc.)

# Performance Measures Suggested for Future



- Measures related to specimen quality
  - Unsatisfactory specimen rates
  - Specimen card field completion rate
  - Inadequate specimen rate
  - Hospitals to be informed about number of unsatisfactory specimens etc.

# Performance Measures Suggested for Future



- Measures related to demographic information/birth records
  - Number (%) of births matched with screening records
  - Number (%) of births with documented screening completed
  - Demographic data errors

# Performance Measures Suggested for Future



- Measures related to feedback
  - Long-term follow-up for patient outcomes
  - False negative rate
  - False positive rate
  - False positive rate with second tier testing
  - Periodic distribution of educational materials to families
  - Number (%) of diagnosed cases reported to national system as they are received (*without waiting until a specific time*)
  - Number (%) lost to follow-up
  - Number (%) “no diagnosis for greater than one year”

# Conclusions



- Pre- and post-analytical measures collected by all states
- Disparity in:
  - Types of measures collected
  - Reporting agency
  - Frequency of reporting
- Not many measures currently being collected on long-term outcomes
- Measures suggested for the future by some states are already being collected by other states
- Some suggestions for improvement could apply to *all* states
- Need for standardization and uniformity
- Suggested measures match with suggestions made by the TNSPMP stakeholders, validate those suggestions

# Questions?

